

# Rocky Mountain CFIDS FMS Association

"Moving mountains for the CFIDS and Fibromyalgia communities"

March 2007

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Sign up for the Infocus e-news delivered by e-mail monthly at our web site [www.rmcfaf.org](http://www.rmcfaf.org)

### Receive RMCFA Information

RMCFA's new Infocus e news letter replaces the calling tree. Those that would like to continue to receive RMCFA event news and information can sign up for the monthly Infocus e-news at [www.rmcfaf.org](http://www.rmcfaf.org) or contact RMCFA with your address information to receive event information by postal mail.

## What's New at RMCFA

The year 2006 brought new additions to RMCFA with the launch of the RMCFA web site in August and the first monthly INFOCUS e-news letter distributed in September to subscribers by e-mail.

The year 2007 will bring new initiatives to connect RMCFA nationally and to work with medical providers to improve education, awareness and health care of CFIDS and Fibromyalgia in Colorado. The goal of RMCFA is to continue to make a difference in the CFIDS and Fibromyalgia communities.

3-6% of US population has Fibromyalgia and CFS affects over 1 million Americans

More more than Multiple Sclerosis, Parkinson's, Lupus, Lung Cancer or Ovarian cancer - CDC

Our mission will combine support, education, awareness and advocacy expanding on national efforts to end the devastating effects of these illnesses. The kick-off of the CDC and CFIDS Association of America's awareness campaign last June followed up with the November 3rd CDC press conference led to over 100 national press reports. This public awareness is crucial to finding a solution.

### RMCFA Receives Award

RMCFA awarded Pandora Sand Castles award and scholarship to attend the 2007 IACFS conference in Florida. The 8th annual IACFS conference January 10-14 presented researchers and clinicians from around the world to share research and information on CFS and Fibromyalgia. The 5 day conference featured both a patient and provider conference.

### Upcoming Event Schedule

Saturday, March 24 - 1 PM

Karen Falbo, CN

*Dietary Principles to Reduce Pain, Inflammation and Fatigue*  
Green Mountain Vitamin Cottage  
12812 W. Alameda Pkwy - Lakewood

Saturday, April 21 - 1 PM

Dr. Lee Smith

"Fibromyalgia Update" DVD series  
National Jewish Medical and Research Center  
1400 Jackson St. - Denver

Saturday, May 19th - 1PM

Group Discussion Meeting - CFS or FM - Treatment Methods Tried and Results Obtained  
National Jewish Medical and Research Center  
- 1400 Jackson St - Denver

Event schedule subject to change  
Go to [www.rmcfaf.org](http://www.rmcfaf.org) for up to date information

Officers and Directors

Mike Munoz - President

Tim Smith - Secretary/Treasurer

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Please send CFS/FMS Physician/medical provider referrals to [link@rmcfaf.org](mailto:link@rmcfaf.org)

# News Awareness

## Advisory Board Recommends ME Name Change

CFS researchers and clinicians met at the IACFS conference to discuss a name change for 'Chronic Fatigue Syndrome' in light of recent research advances. CFS clinicians and researchers have long held that 'chronic fatigue syndrome' trivializes the serious nature of the disorder, and have called for a change from adopted name by the CDC in 1988.

The committee, called "the *CFS Name Change Advisory Board*" by its organizer, CFS patient Rich Carson, included Drs. Lucinda Bateman, David Bell, Paul Cheney, Charles Lapp, Nancy Kilmas, Anthony Komaroff, Leonard Jason, and Daniel Peterson. 'ME' has historically been used to describe 'Myalgic Encephalomyelitis' (nervous system inflammation involving muscle pain) - a term that does not accurately describe the disease process in all patients.

*Committee members preferred 'Myalgic Encephalopathy' (Nervous system pathology with associated muscle pain), which is also abbreviated 'ME'*

This satisfied the researchers that this form of the term 'ME' is diagnostically accurate. Recent scientific advances point to the usefulness of the ME label, as brain pathology with often painful consequences, especially in muscle, is increasingly documented in patients with this condition.

The group recognized that dropping CFS completely from a new name could cause problems with disability and medical insurance claims, and recommended that 'CFS' should accompany any new name, at least for a period of time. - *Rich Carson*-

## We would like to thank and recognized our 2006 Donors and Volunteers

Judy Bernhardt  
Sharon Bernia  
Tanja Bugas  
Donna Chaney  
Jan Christensen  
Sarah Clausen  
Linda Donnelly  
Carol Faino  
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Carron Taylor  
Bernice Taylor  
Dean Taylor  
Stacey Townsend  
Jane F. Wallace  
Haworth Press  
Knights of Columbus  
National Jewish Medical  
Center  
OFFER

We do our best to recognize everyone who contributed. If we have not recognized your contribution please contact us so we can thank you. If you would like to make a 2007 contribution, please see the enclosed donor card

## Whittemore Peterson Institute for Neuro-Immune Disease breaks ground

The Center for Molecular Medicine at the University of Nevada will house the Whittemore Peterson Institute for Neuro-Immune Disease and the Center for Nevada Cancer Institute. More than 15,000 square feet on the second and third floors will house the Whittemore Peterson Institute, the first institute of its kind in the United States dedicated to finding a cause and cure for CFS and Fibromyalgi. the Whittemore Peterson Institute will not only conduct research in the new facility but will also treat patients and develop educational programs for complex disorders of the immune system and brain.

## Volunteer Bulletin Board

RMCFCA relies on volunteers for Association activities. Please help our efforts by volunteering today.

- \* Meeting and Event assistance
- \* Fund Raising
- \* Marketing, Graphic design and layout
- \* Newsletter writing
- \* Board members
- \* Administrative and clerical duties
- \* Speaker recommendations

Contact us at (303) 423-7367 or e-mail - [link@rmcfa.org](mailto:link@rmcfa.org)

## National Fibromyalgia and CFS Awareness Day May 12

### Lobby Day 2007

Lobby Day promises to be our most exciting and successful event ever on the back of all the recent research news and media campaign! The 15th annual event, advocates will gather in Washington, DC for a training session on Monday, May 14, and then meet with members of Congress and staff on Tuesday, May 15. RMCFCA will be represented by Mike Munoz - President of RMCFCA this year. Anyone who would like to participate contact RMCFCA

### OFFER Patient and Provider Conference

The 2007 OFFER patient and provider conference - May 4 and 5 in Salt Lake City, Utah - Speakers to include Lynne Mataliana, (National Fibromyalgia Association) President, Suzanne Vernon (CDC), Drs. David Bell, Lucinda Bateman, Charles Lapp and more. For more information visit the OFFER web site at [www.offerutah.org](http://www.offerutah.org) or contact RMCFCA for information.